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Limited concordance between teachers, parents and healthcare professionals on the presence of chronic diseases in ID-adolescents

B. Oeseburg^{a,b,*}, D.E.M.C. Jansen^{a,c}, S.A. Reijneveld^a, G.J. Dijkstra^a, J.W. Groothoff^a

^a Department of Health Sciences and Graduate School for Health Research (SHARE), University Medical Center Groningen, University of Groningen, The Netherlands

^b Wenckebach Institute, School of Nursing and Health, University Medical Center Groningen, Groningen, The Netherlands

^c Department of Sociology, Faculty of Behavioral and Social Sciences, University of Groningen, The Netherlands

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ABSTRACT

Evidence on teachers' knowledge about somatic and mental chronic diseases among ID-adolescent compared to the knowledge parents and healthcare professionals have, is limited. The aim of this study is: (1) to assess the knowledge of teachers on the presence of chronic diseases in ID-adolescents; (2) to compare teachers with parents and healthcare professionals and parents with healthcare professionals regarding the knowledge on the presence of chronic diseases in ID-adolescents. We obtained data on 1044 ID-adolescents attending secondary schools, fully covering one region of the Netherlands. Teachers, parents and general practitioners (GPs) of the adolescents completed a questionnaire about the occurrence of chronic diseases in their child during the previous 12 months. The questionnaire was derived from the Dutch National Permanent Survey on Living Conditions questionnaire periodically administered in a representative population sample ($n \approx 10,000$). Concordance between teachers, parents and healthcare professionals on the presence of chronic diseases in ID-adolescents was relatively low. In about half of all 66 dyads the concordance was for the most part fair and just in 10 dyads good to very good; nine of these latter cases concerned somatic chronic diseases. In addition, teachers reported mostly lower prevalence rates of chronic diseases in ID-adolescents compared to the parents, in particular on mental chronic diseases. Although prevalence rates of chronic diseases among ID-adolescents are very high, knowledge on this among teachers is limited. While information on chronic diseases in ID-adolescents is available among different informants, the disagreement between them reflects different points of view between the informants and probably indicates a lack of communication. The communication among teachers, parents and GPs should be improved to combine the knowledge and information on the presence of chronic diseases in ID-adolescents. This may provide opportunities to improve the support of these adolescents in their school career and in their transition from school to work.

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1. Introduction

Chronic diseases are more prevalent among adolescents with intellectual disability (ID-adolescents) than among adolescents without ID (Emerson & Hatton, 2007; Emerson, 2003; Magnusson & Saemundsen, 2001; Oeseburg, Jansen,

* Corresponding author at: University Medical Center Groningen (UMCG), Department of Health Sciences and Graduate School for Health Research (SHARE), P.O. Box 30.001, 9700 RB Groningen, The Netherlands. Tel.: +31 050 363 8914; fax: +31 050 363 62.

E-mail address: b.oeseburg@med.umcg.nl (B. Oeseburg).

Dijkstra, Groothoff, & Reijneveld, 2010; Petterson, Bourke, Leonard, Jacoby, & Bower, 2007; Voigt, Barbaresi, Colligan, Weaver, & Katusic, 2006). Several studies have indicated that chronic diseases in *ID-adolescents*, in particular mental chronic diseases, largely increase the likelihood of emotional and behavioral problems (Bradley, Summers, Wood, & Bryson, 2004; Brereton, Tonge, & Einfeld, 2006; Buelow et al., 2003; Cormack, Brown, & Hastings, 2000; Hill & Furniss, 2006; Lewis et al., 2000; Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010). Both, emotional and behavioral problems and disease specific problems, such as pain, fatigue or deficits in attention or hyperactivity, have a profound effect on participation of ID-adolescents in educational programs, occupational opportunities, and also on the potential to live in the community (Einfeld et al., 2006; Emerson & Hatton, 2007; Kanne, Abbacchi, & Constantino, 2009; Oeseburg, Jansen, Dijkstra, et al., 2010; Oeseburg, Jansen, Groothoff, et al., 2010; Reijneveld et al., 2003; Turk, Graham, & Verhulst, 2007).

Adequate school support highly contributes to the educational achievements of adolescents and their subsequent transition to employment (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Nabors, Little, Akin-Little, & Iobst, 2008; Patel, Flisher, Hetrick, & McGorry, 2007; Patton & Viner, 2007; Sawyer, Drew, Yeo, & Britto, 2007; Taggart & McMullan, 2007; Turk et al., 2007). Teachers play a pivotal role in the challenging process to prepare adolescent successfully for the workforce. In case of ID-adolescents, teachers are more challenged since most ID-adolescents have chronic diseases which affect educational success (Clay et al., 2004; Mukherjee, Lightfoot, & Sloper, 2000; Nabors et al., 2008; Taggart & McMullan, 2007). Therefore, information on chronic diseases among ID-adolescents is highly needed by teachers, since it may help teachers to manage the effects of chronic diseases on the adolescents' emotional and behavioral functioning and their disabilities.

The limited evidence as available shows that teachers' knowledge about chronic diseases of their ID-adolescent students is much less than needed. This may be due to the fact that parents and healthcare professional do not share this information with teachers (Bishop & Boag, 2006; Clay et al., 2004; Nabors et al., 2008; Taggart & McMullan, 2007). Diagnostic overshadowing among teachers may be the result, i.e. teachers attribute the adolescents' problem behavior and disabilities to their ID rather than to other, potentially manageable causes related to their chronic disease(s) (Jopp & Keys, 2001). This misattribution may lead to the maintenance or aggravation of problem behavior because effective interventions to prevent symptoms of the disease that elicit problem behavior will not be used.

The aim of this study is therefore: (1) to assess the knowledge of teachers on the presence of chronic diseases in ID-adolescents; (2) to compare teachers with parents and healthcare professionals and parents with healthcare professionals regarding this knowledge on the presence of chronic diseases in ID-adolescents.

2. Methods

2.1. Participants

2.1.1. Sample

We collected data in 2006–2007 on adolescents with a borderline, mild, moderate or severe ID aged 12–18 years living in two provinces in the north of the Netherlands, Groningen and Drenthe (total population about 1.1 million people). Nearly all adolescents of the target population attended secondary schools (schools for practical training) or special secondary schools (regional expertise centers). ID-adolescents attending schools for practical training can be classified as mainly educable and have IQs between 60 and 80. ID-adolescents attending regional expertise centers can be classified as mainly trainable and have IQs between 30 and 60 (Dekker, Koot, van der Ende, & Verhulst, 2002). ID-adolescents not attending secondary schools, most of them with profound ID, were not included. The target population had been officially classified as having ID by an independent committee established by The Dutch Ministry of Education, Culture and Science. The classification of ID is based on information from validated intelligence tests (Dutch Eurydice Unit, 2007).

In the current school-based cross-sectional study, 88% of the schools for practical training and regional expertise centers in both provinces participated. Non-participating schools did not differ from participating schools regarding urbanization of the catchment area and number of students. All parents of the 2156 adolescents aged 12–18 years received a questionnaire and a reminder when they did not respond. One thousand forty four parents (48%) returned the questionnaire. Adolescents in the response and non-response group did not differ regarding age (t -test = 1.751, ns), but the response group had a higher proportion of girls ($\chi^2 = 5.9$; $p < 0.05$) and a higher proportion of adolescents with borderline or mild ID ($\chi^2 = 9.8$; $p < 0.05$). However, the effect sizes for both variables were trivial; Cohen's w were 0.06 and 0.07, respectively (Cohen, 1988).

2.1.2. Subsample with data from parents, teachers and general practitioners

Additionally, parents were asked for informed consent to derive information on chronic diseases of their child from their teacher and healthcare professionals, in this case general practitioners (GPs). GPs are in the Netherlands the best setting to provide valid information on common and lifelong health problems (Westert et al., 2005). Eight hundred ninety one (85%) parents gave informed consent. Teachers and GPs returned the questionnaires of 767 (86%) and 724 (81%) adolescents, respectively. Data on the presence of chronic diseases in ID-adolescents from all three informants were available for 539 adolescents. These 539 adolescents did not differ regarding gender ($\chi^2 = 0.4$; $p = 0.54$) and IQ ($\chi^2 = 3.4$; $p = 0.06$), but they were older (t -test = 2.2, $p < 0.05$) compared to the non-response group within this sub sample. However, the effect size was trivial; Cohen's d was 0.12 (Cohen, 1988).

The study protocol was approved by the Medical Ethics Committee of the University Medical Center Groningen, the Netherlands.

Table 1
Demographic characteristics of the sample.

Age (N = 539)	Years
Mean	15.7
SD	1.7
Range	12–18
Gender (N = 538)	N (%)
Boys	319 (59.3)
Girls	219 (40.7)
Level of ID ^a (N = 539)	N (%)
IQ 60–80	416 (77.2)
IQ 30–59	123 (22.8)

^a As measured by school type.

2.2. Measures

2.2.1. Chronic diseases in ID-adolescents

Chronic diseases in ID-adolescents were measured by the National Permanent Survey on Living Conditions questionnaire (POLS); module health and labor, part chronic diseases in children (Statistics Netherlands, 2003). POLS was developed by Statistics Netherlands and is yearly used in a representative sample ($n \approx 10,000$) of the Dutch population (Otten & Winkels, 1998). POLS part chronic diseases in children covers the most prevalent chronic diseases such as: ear, eye, skin diseases, diseases of the nervous, musculoskeletal, blood and circulatory, respiratory, digestive, and endocrine, nutritional and metabolic systems and attention deficit hyperactivity disorder (ADHD). Questions were added about the presence of pervasive developmental disorders (PDD). Parents, and if informed consent was obtained from the parents, also teachers and GPs were asked to report the presence or absence of each specific chronic disease in the last 12 months for their child, pupil, or patient, respectively. They could also report the presence of chronic diseases that were not listed in the questionnaire.

2.2.2. Background characteristics

The questionnaire comprised questions on age, gender and school type of the adolescent. School type was used as proxy for severity of ID.

2.3. Analysis

First, we computed prevalence rates of the separate chronic diseases, based on teachers', parents' and GPs' report in 539 ID-adolescents. Second, we compared the prevalence rates teachers reported on the separate chronic diseases in ID-adolescents with that of the parents and GPs, respectively. In addition, the prevalence rates parents and GPs reported on the separate chronic diseases in ID-adolescents were compared. Differences were tested using chi-square tests and for all differences effect sizes according to Cohen, Cohen's h , were calculated (Cohen, 1988). Cohen (Cohen, 1988) defines an effect size of <0.20 as trivial; of ≥ 0.20 to <0.50 as small; of ≥ 0.50 to <0.80 as moderate; and of ≥ 0.80 as large effect. Finally, the concordance between the knowledge of the three informants on the presence of chronic diseases in ID-adolescents was measured using Cohen's kappa for three dyads: teacher–parent, teacher–GP and parent–GP. We used the guidelines for interpretation of kappa proposed by Landis and Koch (Landis & Koch, 1977). Landis and Koch (Landis & Koch, 1977) defined a kappa of <0.21 as poor agreement; of ≥ 0.21 to <0.41 as fair agreement; of ≥ 0.41 to <0.61 as moderate agreement; of ≥ 0.61 to <0.81 as good agreement; and of ≥ 0.81 to 1.00 as very good agreement.

3. Results

Table 1 shows the background characteristics of the adolescents. The gender ratio, 59.3% boys and 40.7% girls, was similar to the ratio boys and girls with ID in the Netherlands (Schrojenstein Lantman-de Valk, Heurn-Nijsten, & Wullink, 2002).

3.1. Differences between the informants

Table 2 shows that teachers reported statistically significant lower prevalence rates for eight chronic diseases compared to the adolescents' parent. The effect sizes were trivial for four chronic diseases (asthma, chronic bronchitis and COPD, chronic eczema, diseases of neck, shoulder and upper extremities, ADHD), and small for the four other ones (migraine or chronic headache, psoriasis, autistic disorder, dyslexia). Moreover, teachers reported statistically significant higher prevalence rates for two chronic diseases (migraine or chronic headache, dyslexia) compared to the GPs. Both effect sizes were small. Teachers reported statistically significant lower prevalence rates for two chronic diseases compared to the GPs. The effect size was small for asthma, chronic bronchitis, COPD and trivial for congenital malformations nervous system.

Table 2Prevalence rates teachers, parents and GPs reported on the separate chronic diseases in ID-adolescents ($N = 539$) and the differences between the three informants.

	Informants						Differences					
	Teachers		Parents		GPs		Teachers–parents		Teachers–GPs		Parents–GPs	
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	<i>p</i> -Value	<i>h</i> ^a	<i>p</i> -Value	<i>h</i>	<i>p</i> -Value	<i>h</i>
Somatic chronic diseases												
Asthma, chronic bronchitis, COPD	4.3	23	9.3	50	8.9	48	0.001 ^b	0.20	0.002	0.19	0.832	0.01
Cerebral palsy	0.6	3	0.7	4	0.6	3	0.704	0.02	1.000	0.00	0.704	0.02
Chronic eczema	1.7	9	4.8	26	2.4	13	0.003	0.18	0.389	0.05	0.033	0.13
Congenital malformations circulatory system	0.9	5	1.9	10	2.2	12	0.194	0.08	0.087	0.11	0.667	0.03
Congenital malformations nervous system	2.0	11	2.4	13	5.6	30	0.676	0.03	0.002	0.19	0.008	0.16
Congenital malformations eye	1.1	6	2.0	11	1.5	8	0.217	0.08	0.583	0.03	0.487	0.03
Congenital malformations ear	1.9	10	1.3	7	1.5	8	0.463	0.04	0.635	0.03	0.795	0.02
Chromosome abnormalities	2.8	15	3.5	19	3.2	17	0.486	0.15	0.720	0.02	0.735	0.02
Diabetes	1.1	6	0.4	2	0.2	1	0.156	0.09	0.058	0.13	0.563	0.04
Epilepsy	3.7	20	4.3	23	5.4	29	0.641	0.03	0.189	0.08	0.394	0.05
Gastrointestinal and liver diseases	1.7	9	1.3	7	0.7	4	0.614	0.03	0.163	0.04	0.363	0.06
Heart- and blood diseases	2.2	12	2.6	14	1.5	8	0.691	0.02	0.367	0.05	0.196	0.08
Migraine or chronic headache	7.1	38	14.7	79	1.3	7	0.000	0.25	0.000	0.31	0.000	0.56
Muscular diseases	0.6	3	1.1	6	0.2	1	0.315	0.06	0.316	0.06	0.058	0.13
Musculoskeletal diseases												
Diseases of the back	2.2	12	2.8	15	2.2	12	0.559	0.04	1.000	0.00	0.559	0.04
Inflammatory polyarthropathies	0.6	3	0.7	4	0.4	2	0.705	0.02	0.654	0.03	0.413	0.05
Diseases of neck, shoulder and upper extremities	2.2	12	5.9	32	1.3	7	0.002	0.19	0.247	0.07	0.000	0.26
Psoriasis ^c	0.0	0	1.1	6	0.2	1	0.014	0.21	0.317	0.09	0.058	0.13
Mental chronic diseases												
Attention deficit/hyperactivity disorder (ADHD)	16.7	90	22.8	123	16.5	89	0.012	0.15	0.935	0.01	0.009	0.16
Autistic disorder	3.5	19	10.8	58	2.2	12	0.000	0.28	0.202	0.08	0.000	0.37
Dyslexia	5.9	32	14.1	76	1.5	8	0.000	0.28	0.000	0.25	0.000	0.53
Pervasive developmental disorder not otherwise specified (PDD-NOS)	11.5	62	13.9	75	10.2	55	0.235	0.07	0.493	0.04	0.061	0.11

^a *h* = Cohen's *h*.^b Bold differences are statistically significant.

Table 3

Concordance between the knowledge of the three informants on the presence of chronic diseases in ID-adolescents measured by Cohen's kappa.

	Teachers–parents Cohen's kappa	Teachers–GPs Cohen's kappa	Parents–GPs Cohen's kappa
Somatic chronic diseases			
Asthma, chronic bronchitis, COPD	0.35	0.24	0.39
Cerebral palsy	0.57	0.33	0.28
Chronic eczema	0.27	0.26	0.29
Congenital malformations circulatory system	0.53	0.11	0.35
Congenital malformations nervous system	0.74^a	0.42	0.45
Congenital malformations eye	0.22	0.01	0.09
Congenital malformations ear	0.58	0.55	0.53
Chromosome abnormalities	0.82	0.87	0.83
Diabetes	0.25	0.28	0.67
Epilepsy	0.59	0.55	0.72
Gastrointestinal and liver diseases	0.24	0.30	0.17
Heart- and blood diseases	0.53	0.39	0.44
Migraine or chronic headache	0.24	0.11	0.10
Muscular diseases	0.44	0.50	0.28
Musculoskeletal diseases			
Diseases of the back	0.67	0.49	0.51
Inflammatory polyarthropathies	0.57	0.80	0.67
Diseases of neck, shoulder and upper extremities	0.33	0.10	0.09
Psoriasis	– ^b	–	–
Mental chronic diseases			
Attention deficit/hyperactivity disorder (ADHD)	0.59	0.59	0.57
Autistic disorder	0.30	0.44	0.20
Dyslexia	0.39	0.03	0.00
Pervasive developmental disorder not otherwise specified (PDD-NOS)	0.67	0.51	0.53

^a Bold kappas are good to very good.^b Value of kappa was not meaningful to report because teachers did not report any case of psoriasis in ID-adolescents and GPs just one case of psoriasis in ID-adolescents.

We also analyzed the dyad parents–GPs. GPs reported statistically significant higher prevalence rates for congenital malformations of the nervous system compared to the parents. However, the effect size was trivial. Parents reported statistically significant higher prevalence rates for six chronic diseases compared to the GPs. The effect sizes were trivial for chronic eczema and ADHD, small for diseases of neck, shoulder and upper extremities and autistic disorder, and moderate for migraine or chronic headache and dyslexia.

3.2. Concordance between the informants

Table 3 shows that in about half of all 66 dyads concordance was poor to fair. In 10 of all dyads the kappas ranged from good to very good. This occurred four times in the dyad teachers–parents, four times in the dyad parents–GPs and two times in the dyad teachers–GPs. In nine cases, it concerned somatic chronic diseases and in one case a mental chronic disease.

4. Discussion

This study shows that the concordance between teachers, parents and healthcare professionals on the presence of chronic diseases in ID-adolescents was relatively low. In about half of all 66 dyads the concordance was at most fair and just in 10 dyads good to very good.

4.1. Fit with other studies

To our knowledge, no previous studies have examined the knowledge of teachers on the presence of a wide range of chronic diseases in ID-adolescents, and compared this with the knowledge parents and GPs have. However, we can state that our findings are mostly in line with studies reporting on a lack of information among teachers on issues associated with chronic diseases. These studies showed that teachers have limited knowledge regarding chronic disease-related information and limited confidence on their ability to work with children and adolescents with chronic diseases (Bishop & Boag, 2006; Brook & Galili, 2001; Clay et al., 2004; Mukherjee et al., 2000; Nabors et al., 2008; Taggart & McMullan, 2007). Moreover, our results are in line with studies on inter-informant agreement. These studies also reported limited concordance between different informants. Disconcordance may be due to variations in situation of informants and due the nature of the problems: parents versus teachers, internalizing versus externalizing problems, visible versus not visible problems (Achenbach, McConaughy, & Howell, 1987; Meester-Delver et al., 2008; Reijneveld, de Meer, Wiefferink, & Crone, 2008).

Our study shows that teachers reported mostly lower prevalence rates of chronic diseases in ID-adolescents than their parents, in particular on mental chronic diseases. In addition, this study shows that teachers and GPs and parents and GPs also reported different prevalence rates of chronic diseases in ID-adolescent. Thus, when information on chronic diseases in ID-adolescents is available among different informants and the disagreement between them reflects different points of view between the informants and probably indicates a lack of communication between them.

4.2. Strengths and limitations

Important strengths of this study are that it examined the prevalence rates of a wide range of chronic diseases in ID-adolescents in a community-based sample representative for about 90% of the adolescents with ID. Another strength is the use of multi-informant information and the comparison of the similarly obtained data and the high response rates of teachers and GPs in our sub sample. A limitation is the relatively low response rate of the total sample (48%). This could have lead to selection bias, but non-response analyses revealed no major differences in response by age, gender and educational level.

4.3. Implications for practice

Teachers need to be fully aware of the presence of chronic diseases in ID-adolescents and the impact on their functioning in order to meet their needs and to support them successfully in the transition from school to work. They need professional advice to handle the problems of adolescents with ID and chronic diseases in their classroom (Bishop & Boag, 2006; Brook & Galili, 2001; Clay et al., 2004; Mukherjee et al., 2000; Nabors et al., 2008). Information from parents or healthcare professionals on the presence of chronic diseases in ID-adolescents could improve teachers' awareness of chronic diseases in ID-adolescents and the impact on their functioning, and could improve their confidence to support them adequately. However, arrangements must be found to improve the communication among teachers, parents and GPs to combine the knowledge and information on the presence of chronic diseases in ID-adolescents (Clay et al., 2004; Mukherjee et al., 2000; Nabors et al., 2008; Perrin, Lewkowicz, & Young, 2000; Wolraich et al., 2004). Parents are in this communication process crucial because they are in the position to inform both teacher and GP about the health condition of their child. Moreover, teachers and GPs need their informed consent to transfer information on the health condition of the adolescent.

4.4. Implications for research

Our study is the first to examine the knowledge of teachers, parents and GP's on the presence of a wide range of chronic diseases in ID-adolescents. Therefore, our findings need confirmation including an assessment of the validity of the knowledge of each informant. Moreover, future research should examine whether arrangements to improve the communication among teachers, parents and GPs will be effective (Clay et al., 2004). Our results show very high prevalence rates of chronic diseases among ID-adolescents, and thus a high need for informed and skilled teachers to support these ID-adolescents in their school career and in their transition from school to work.

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